Child Protection Accountability Commission
Training Committee
De-Escalation of Life Support Workgroup
February 7, 2018
A.I. duPont Hospital for Children

Meeting Minutes

In Attendance:

Carole Davis, Esq.	Department of Justice
Dr. Allan De Jong	A.I. duPont Hospital for Children
Dr. Stephanie Deutsch	A.I. duPont Hospital for Children
Susan Gordon, Esq.	Christiana Care
Mark Hudson, Esq., Co-Chair	Office of the Child Advocate
Honorable Peter B. Jones	Family Court
Jennifer Macaulay	A.I. duPont Hospital for Children
Dr. Elissa Miller	A.I. duPont Hospital for Children
Phyllis Rosenbaum, Esq.	A.I. duPont Hospital for Children
Susan Taylor-Walls	Division of Family Services
Janice Tigani, Esq.	Department of Justice

I. Welcome and Introductions

The Co-Chair opened the meeting and attendees introduced themselves.

II. Approval of Minutes – 6/14/17 Meeting

The draft minutes were approved as written.

III. Discussion of Multidisciplinary Response Area 2: Court Action

a. Appeal

The group had a brief follow-up discussion concerning appellate issues that were left open at the conclusion of the last meeting. As discussed at the last meeting, the co-chairs reached out to the Office of Disciplinary Counsel (ODC) for guidance on counsel's obligation to alert the Supreme Court if there are any changes in the child's status during the pendency of an appeal. While not able to offer direct advice, the ODC suggested the review of several of the Delaware Lawyers' Rules of Professional Conduct, most notably, Rule 3.3, Candor toward the tribunal. The consensus of the group is that, should the child's status change during the pendency of an appeal,

all counsel should err on the side of disclosure to avoid the possibility of withholding potentially relevant information from the Supreme Court.

As discussed at the last meeting, the co-chairs also contacted the Supreme Court about counsel's ability to request oral argument. Staff at the Supreme Court Clerk's Office indicated that counsel could always file a written request for oral argument, but that the Court has discretion in granting it.

b. Independent Medical Evaluation

The workgroup discussed the need for an independent medical evaluation in the cases falling under the purview of this workgroup. In the *Hunt* case, the Supreme Court ordered an independent medical evaluation, at least in part, because the Family Court had previously stated that an independent medical evaluation was required. The workgroup discussed whether or not an independent evaluation should be performed where the Family Court is not directly requiring it. The group determined that in such cases where the parents are not opposed to de-escalation of care or no one is specifically requesting an independent evaluation, then one need not be sought or performed.

In cases where parents are opposed to de-escalation or an independent medical evaluation is specifically requested by a party, then the group agreed that best practice is to have an independent medical evaluation performed. That said, the group acknowledged that this best practice may not always be feasible in every case due to several difficulties inherent in obtaining independent medical evaluations in Delaware.

One of the biggest difficulties in obtaining an independent medical evaluation in Delaware is the result of the small size of our state and the limited number of qualified doctors to perform such an evaluation. The group discussed that because of the typical nature of the injuries in these types of cases, a pediatric neurologist will likely be required to perform the evaluation. Presently, there is only one pediatric neurologist in Delaware not directly employed by A.I. duPont Hospital for Children, and even he is not completely unaffiliated with that hospital. It is possible that a neurosurgeon could perform the independent medical evaluation, but the same problem exists. The workgroup discussed if staff at A.I. duPont Hospital for Children could attempt to network with other area hospitals to gauge willingness to provide independent medical opinions in future cases that may arise. Hospital representatives stated that those decisions are typically made on a case-by-case basis and attempting to establish a network for unspecified future cases likely will not be successful. Drs. De Jong and Deutsch indicated that they could reach out to their colleagues at Children's Hospital of Philadelphia to see how they handle similar cases. Also, it was discussed that counsel in any given case can contact the state or national medical boards for lists of pediatric neurologists locally or nationally.

There was brief discussion about the possibility of isolating a doctor at A.I. duPont Hospital for Children who could then give an "independent" evaluation without any influence from his or her colleagues. This option did not seem realistic because the doctors meet regularly to discuss patients and it would be nearly impossible for another qualified doctor in the hospital not to have knowledge of a patient in a case where de-escalation was being recommended.

It was discussed that the independent medical evaluation is largely a review of records and it could potentially be performed by telemedicine. If that is the case, Nemours has a hospital in Orlando, Florida with doctors who could potentially provide a second opinion, particularly if they do not have to physically appear in Delaware for the evaluation or testimony. The group discussed whether or not an evaluation from a doctor employed by Nemours, just in another state, would be truly "independent." While a wholly unaffiliated doctor would naturally be preferable to a doctor in any way associated with the child's treating hospital, given the historic difficulty in locating such a doctor and the need to resolve these cases quickly, the doctors at the Nemours Children's Hospital in Orlando, Florida, could be a viable last resort. One problem noted with this potential solution is that if a parent takes issue with the accuracy of A.I. duPont's medical records and that is what the independent doctor is primarily relying upon, then it could raise questions about the accuracy of the second opinion.

Lastly, it was suggested that the child could be transferred to another hospital as a means of obtaining another independent opinion on the course of the child's treatment. In addition to the possibility that the child may not be stable enough to be transported or that another hospital might not accept the child as a patient, such a tactic would be a significant disruption to the child's care if used solely as a means of obtaining a second opinion. The group did not find this to be a realistic solution.

Another difficulty with obtaining independent medical evaluations stems from other doctors not wanting to become involved in on-going litigation. In the *Hunt* case, at the direction of the Supreme Court, the Family Court issued an order providing the independent doctor all of the immunities afforded to the Court and protecting the doctor from being deposed or testifying. This was important to Dr. Fischer in agreeing to evaluate the child in *Hunt*. While it is uncertain if the Family Court has the power to issue such an order without the Supreme Court's direction, the Family Court has recently issued an identical order in another case. Judge Jones agreed to follow-up with the other Family Court Judges regarding the issuance of such an order and inform the workgroup accordingly. The group discussed briefly whether it would be preferable for a doctor affiliated with the child's treating hospital (i.e. a doctor from Nemours in Florida), but required to

testify, to perform the evaluation or a doctor less affiliated but protected from testifying or being deposed. If presented with those alternatives, it will be up to counsel in that particular case, likely parents' counsel, to decide which, if either, of those options is preferred.

Another important consideration when determining whether or not an independent medical evaluation should be conducted in any particular case is timing. As discussed in previous workgroup meetings, time is of the essence in these cases. The question was raised concerning the need for an independent medical evaluation in any case if there are multiple credible and qualified doctors all testifying to the same thing. In the absence of the Court finding a factual need for a second opinion, the justification for a second opinion devolves most strongly from due process protections afforded to the parents; a parent has the right to call witnesses in defense of his or her position. That said, how much time should the Court give a party to secure the opinion and testimony of an independent doctor? To answer that question, the workgroup examined what period of time reasonably affords parties the opportunity to locate an independent doctor to perform an evaluation of the child, while taking into account needs of the child to have a timely decision. The medical professionals in the workgroup reported that if enough time passes, it is likely that any child will be able to have his or her ventilator removed and breathe independently, however, that will not change the fact that the child is neurologically devastated. That said, re-intubation in the future is inevitable and timing is important because of the suffering of the child. Given the urgency of these cases, the workgroup concluded that two weeks provides parties adequate opportunity to report to the Court that either a doctor has been located who can perform an evaluation or that the parties have been unsuccessful in finding an independent physician. While the evaluation may not be able to be performed in that two week period, that period of time affords the parties reasonable opportunity to locate an independent doctor.

The workgroup discussed that when the Family Court is in need of an independent medical evaluation to issue a fully informed order, the Family Court should, of course, order that such an opinion is required. In instances where the Family Court has sufficient evidence to make a decision on de-escalation without an independent medical evaluation, but a party is requesting one, the Family Court should be careful in its order not to state that such an evaluation is "required," but that it will afford the parties an "opportunity" to obtain a second opinion. In such scenarios, the Court should place time limits on locating an independent doctor, as stated above.

In terms of payment for the independent medical evaluation, the group discussed that, as the request will typically be coming from an indigent parent, the Family Court will typically pay for the evaluation. That said, Family Court has limits on what it can pay. For example, while the Court

may be willing to pay roughly $2,000, it is unlikely that the Court will pay $10,000.

c. Miscellaneous

In light of a recent, on-going case wherein de-escalation of a child's care is being recommended, the co-chairs reached out to counsel for one of the parents in that case, Kelly Sasso, Esquire, for input on how the process has been. Ms. Sasso felt that her involvement in the hospital meetings was important to her client but that she did not know what to expect at those meetings. Ms. Sasso said that the child's attorney was very communicative and that was helpful. Lastly, Ms. Sasso said that the number of people involved in these cases can be confusing and that a list of team members could be useful.

Based on Ms. Sasso's input, the group determined that training is needed for parent attorneys so that they know what to expect when representing parents in these cases. Additionally, parent attorneys should receive training so that they can adequately explain the process of these unique cases to their clients. The group also decided it would be best practice for a list of team members to be circulated to all team members and counsel so that there is less confusion about who is involved in the legal proceedings and the child's care and what their roles are.

Hospital staff raised the question about contact with incarcerated parents in situations involving de-escalation of care. Typically, hospital staff makes no efforts to involve incarcerated parents, but it was discussed that the hospital may wish to have an incarcerated parent involved if that parent can be an appropriate medical decision maker. Incarcerated parents in cases that fall within the purview of this protocol will likely have appointed counsel who should be active in advocating for his or her client's involvement as requested by the client or the hospital. If the hospital has difficulty with getting a correctional institution to allow a parent's participation or communication with the hospital, this difficulty should be brought to the Family Court's attention so that it can take appropriate action.

Lastly, hospital staff pointed out that in cases where parents do not speak English, it has an interpretation service, but that service is only permitted to interpret for hospital staff and the parents. For example, if a DFS worker is present, the hospital interpretation service cannot interpret what the DFS worker is saying to the parent and vice versa. With this in mind, DFS should

arrange for interpreters at any hospital meetings where parents do not speak English. If needed, DFS can seek assistance from the Court to provide appropriate interpreters.

IV. Discussion of Multidisciplinary Response Area 3: Implementation of Order and Aftermath

The workgroup discussed that in the *Hunt* case, the hospital waited three days after receiving the final order (after appeal to the Delaware Supreme Court) before executing the order. After receipt of the final order, the workgroup agreed that it is best practice for the team to hold a brief conference or teleconference, including hospital staff, DFS, counsel for DFS, counsel for the child, and counsel for parents, to discuss implementation of the order and the plan after the child passes away. This initial meeting should not include the parents as it will be largely logistical. But after this meeting, a brief meeting with hospital staff, DFS, and the parents should occur to discuss implementation of the order, the parents' opportunity to spend time with the child (if appropriate), and arrangements after the child passes. For the child's remains to be removed from the hospital, a parent or relative must sign paperwork at the hospital, so this should be discussed as well.

After the child passes, the child's attorney should be in communication with counsel for the parents about funeral arrangements to ensure that the parents are appropriately included. Members of the workgroup noted, that multiple funeral homes in Wilmington offer funeral services for children in these situations for free or for a very small fee associated with the purchase of an urn.

V. Next Meeting Date

The next meeting will be held on April 6, 2018 from 1:00 to 3:00 p.m. The meeting will be held at A.I. duPont Hospital for Children, with video conferencing to the Sussex County Family Courthouse as well as a telephone conference call line.

VI. Public Comment

There were no members of the public present.

VII. Adjournment

The meeting was adjourned at 4:00 p.m.